**Transitioning Residents from Nursing Facilities to Community Living: Who Wants to Leave?**

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**ABSTRACT**

**OBJECTIVES**: This study examined nursing facility residents' or their legal proxies' perspectives on transitioning out of nursing facilities by assessing residents' ability to live more independently, their preference to leave the facility, and the feasibility to transition with requisite community support.

**DESIGN**: Analysis of survey findings from the California Nursing Facility Screen.

**SETTING:** Eight nursing facilities in southern California.

**PARTICIPANTS**: We targeted all custodial, long-stay residents receiving Medi-Cal (California's Medicaid program, n=218). Of these, 121 (56%) self-consenting residents or legal proxies were interviewed. No presumptions were made as to which residents were appropriate candidates for transition based on health or functional capacity.

**MEASUREMENTS:** California Nursing Facility Screen contains 27 open- and closed-ended questions on preference, ability, and feasibility of transitioning.

**RESULTS**: Twenty-three percent believed that the resident had the ability to transition, 46% indicated a preference to transition, and after discussing potential living arrangements and services, 33% thought that transitioning would be feasible. Among those who consented to allow access to their Minimum Dataset 2.0 (MDS) information (n=41; 34% of the sample), agreement in the assessment of preference was found in 39% of cases.

**CONCLUSION:** Transition decisions are complex and include preference as well as perceptions of the resident's ability to live in a more independent setting and the feasibility of transitioning. Compared to the MDS, we identified a higher proportion of residents who want to transition, suggesting that a systematic approach to assessing the complex decision to transition is needed.

**Key words:** custodial care, nursing facility residents, living arrangements, relocation

## INTRODUCTION

For over two decades, long-term care policy efforts have focused on developing home and community-based alternatives to institutionalization. In 1999, these efforts became a federal imperative with the Olmstead Decision, in which the Supreme Court determined that unnecessary institutionalization violates the Americans with Disabilities Act of 1990 (ADA) (1). States, mandated to administer programs and activities in the most integrated setting appropriate(2) have responded by: 1) diverting persons at risk of nursing facility placement to other settings; 2) delaying entry into the nursing facility; and 3) identifying and transitioning nursing facility residents back into community settings. These strategies have been supported by federal rebalancing initiatives that shift public long-term care dollars toward community-based options and “Money Follows the Person” grants that promote flexible financing systems that follow the individual to the most appropriate care setting. Although an extensive literature focuses on strategies to divert and delay nursing facility placement, comparable information about transitioning long-stay residents out of nursing facilities is lacking.

While it is clear that the majority of community-dwelling older adults wish to remain in their own homes (3), little is known about the extent to which long-stay nursing facility residents of any age prefer to transition to community settings or to remain in an institutional setting. The purpose of the present study was to use a comprehensive instrument to explore three interrelated dimensions inherent in the decision of long-stay residents to transition out of the facility: 1) the resident’s current ability to leave, 2) preference to leave, and 3) the feasibility of transitioning based on possible community-based supports.

**Understanding the Preferences of Nursing Facility Residents**

Both the admission and annual assessments of the Minimum Dataset 2.0 (MDS), completed for all residents in state and federally certified nursing facilities, include one question about the resident's preference to return to the community. However, this single screening question is not uniformly asked of every resident and instructs assessors to use indirect questions with long-stay residents to avoid creating unrealistic expectations: "It's been about 1 year that we've known each other. How are things going for you here at (facility)(4)?"

The indirect approach is defensible if residents are clear and spontaneous in expressing preferences. However, long-stay residents may not consider transitioning an option because of a loss of prior housing or an unquestioning acceptance of facility life. For example, a study of residents in three nursing facilities who were identified by nurses as having light care needs indicated that 70% (n=20) did not want to remain in the facility, but all but one believed that they had no other option (5). Lack of resources or inability to identify and access community-based resources (e.g., accessible housing and transportation) is a significant barrier for long-stay residents (6).

We are not aware of other instruments that systematically assess all long-stay nursing facility residents receiving custodial care or gather comprehensive information on various dimensions of the transition decision using standardized protocols. Instruments such as the MDS allow interviewers wide flexibility in how or even if preference questions are asked. Apart from the MDS, it is not clear that other studies have included residents with dementia in transition interviews and if so, how many residents could not respond or had proxies designated to make health care decisions. A clear description of when proxies are used is an important issue in research with long-stay residents.

The present study targeted long-stay custodial care residents funded by Medicaid, and excluded those admitted for short-stay Medicare-funded rehabilitation, which is a crucial distinction in research (7,8). One study found that residents with Medicare-covered stays were nearly three times more likely to be discharged than residents not covered by Medicare, whereas those relying on Medicaid were almost four times more likely to remain in the nursing facility than those whose stay was not Medicaid-funded (9).

Using a comprehensive transition screen, the following questions were addressed of residents or where necessary, their proxies: 1) What proportion of long-stay residents had the ability to transition from the nursing facility to a community-based setting? 2) What proportion preferred to leave the facility, 3) What proportion of residents believe that transition is feasible after discussing the available community services and supports? 4) Are residents' transition decisions stable over time? 5) Compared to the MDS, does using a comprehensive screen identify a different rate of preference to transition when interviewing all custodial residents funded by Medi-Cal (California's Medicaid program) within select nursing home facilities?

## METHODS

### The Development of the California Nursing Facility Transition Screen

The screen was developed based on reviews of other instruments such as the MDS and input from key stakeholder groups representing persons with disabilities and older adults. Extensive feedback on an initial draft was obtained from representatives of advocacy groups, provider groups, and community agencies. Preliminary drafts were also revised based on pilot tests in two southern California nursing facilities. Criteria for the screen were that it assessed preference from all Medi-Cal residents within a facility, included information on community supports to help the resident determine the feasibility of transitioning, was not taxing to complete, and did not create unrealistic expectations about transitioning opportunities. The University of California Los Angeles Institutional Review Board approved all facets of the project. The interview includes 27 open- and closed-ended questions that examine reasons for entering the nursing facility, preference to transition, and ability to return to the community. To ensure that respondents are aware of housing and community options before assessing the feasibility of transition, the instrument explores potential living arrangements and services needed (screen is available upon request).

### Participants and Setting

We targeted all English-speaking residents receiving custodial (long-term) care covered by Medi-Cal in eight nursing facilities in Southern California (n=218). Residents paying privately and those receiving Medicare-funded rehabilitation were excluded. Non-English speaking residents (n=4) also were excluded from this pilot phase pending translation to other languages. Seven skilled nursing facilities were affiliated with for-profit nursing facility chains, and one was an independent for-profit facility. Exclusion criteria included nursing facilities that

were primarily locked psychiatric facilities, those that were exclusively rehabilitation or sub-acute facilities, and facilities for the developmentally disabled.

Purposive rather than random sampling was used based on the inclusion and exclusion criteria. A consultant to the California Association of Health Facilities described the nursing facility transition project and the need to recruit homes at a southern California meeting. Eight homes were recruited from a list of nine volunteer facilities, located in the catchment areas of community agencies assisting in transition. Data retrieved from a public California website confirmed that the facilities were not atypical of California homes based on resident population characteristics including age, dementia prevalence, and length of stay.

**Procedure**

With privacy safeguards in place, each nursing facility identified all residents whose stay was funded by Medi-Cal and was expected to be long-term. The resident's face sheet identified self-consenters and those who required a legally designated proxy for health care decisions. Interviewers were graduate students who received four hours of training and conducted practice interviews with participants with oversight from a co-investigator to maximize inter-rater reliability. Because we did not exclude subjects based on cognitive status, the majority had a proxy reflecting the high number of residents with impaired cognitive functioning who reside in nursing facilities. Using an interview script, we contacted self-consenters in person (n=44); 33 (75%) agreed to participate. Proxies for residents who had a legally designated decision-maker were contacted by telephone (n=178) since it was not known when or if the proxy would be visiting the facility in person.

Three attempts were made to contact the proxy via the telephone using a structured telephone script to leave messages, introduce the study, and obtain consent. Seventy-seven

percent (n=134) of proxies were contacted and 88 (66%) agreed to participate. To assess stability, all participants who indicated that transition was feasible were re-interviewed approximately three weeks later. Those who consented to the interview were asked to sign a Health Insurance Portability and Accountability Act of 1996 (HIPAA) consent to access the resident's MDS records. Preference information contained in the most recent full MDS (item Q1.a) was compared with the responses to the California Nursing Facility Transition Screen. Residents who believed that transitioning was feasible were asked to sign a release consent to share their information with the community agencies that would assist them.

Twelve inter-rater reliability interviews were conducted, in which two interviewers coded participants' responses. Agreement was 100% on participants' preference to relocate. We found an 84% agreement and a mean kappa of 0.77 across all numeric items in our instrument. In addition, all proxy respondents were asked for consent to conduct a second interview of the resident to examine proxy reliability issues. Only 9% (8 out of 88) proxies permitted a second interview, and three of these residents did not consent. Of the remaining five cases, both proxies and residents reported the same preference toward relocation.

## RESULTS

### Securing Participation in the Study

As shown in Figure 1, 218 Medi-Cal residents were eligible for the study in eight nursing facilities. Potential participants included 44 (20%) self-consenting residents, and 174 (80%) proxies. Researchers were able to contact 82% of residents or their proxies (n=178). Forty proxies (18%) could not be contacted after three attempts. Sixty-eight percent of those contacted (n=121) consented to the interview, 33 were self-consenting residents (75% of all self-consenters), and 88 were proxies (66% of proxies contacted; 51% of all proxies). Of the 57 participants who did not consent, 41 provided explanations. The most common reason provided was health and/or functional problems that required 24-hour care (n = 27; 47%). Ten noted that they were not interested in the study, three were satisfied with the nursing facility, and one was unwilling to provide personal information. The final analytic sample consisted of 33 residents and 88 proxies, or 56% of all possible participants.

(PLACE FIGURE 1 ABOUT HERE)

### Ability and Preference to Leave the Nursing Facility

Participants were first asked about *ability* to transition: "Do you think you (your relative) would be able to leave the nursing facility and live somewhere else now?" Most (69%; n=84) indicated the resident was not able to leave; 23% (n=28) indicated that the resident was able, and 7% (n=9) were unsure. Although more than twice as many proxy as resident interviews were conducted, only 25% (n=7) of those indicating that the resident had the ability to leave were proxies whereas 75% (n=21) were residents ($\chi^2$= 8.72,*P*=.013). When asked why the resident was unable to leave, 81% (n=68) gave a reason. These included the need for facility level of care

(n=34; 50%), the inability to perform basic activities such as walking or eating (n=23; 34%), and risks involved (e.g., falling, wandering) with leaving the nursing facility (n=4; 6%).

Interviewers then tapped the second component of the decision to leave— *preference*: "Would you (your relative) want to live somewhere other than the nursing facility?" Almost half (n=56; 46%) indicated that the resident wanted to leave the facility; 35% (n=42) said the resident did not want to leave; and 19% (n=23) did not know. A greater percentage of proxies (n=36; 86%) than residents (n=6; 14%) indicated that the resident did not want to leave the nursing facility ($\chi^2$= 16.09, $P$<.001). To determine why participants did not want to transition, they were asked: "What are some reasons you (your relative) want(s) to continue living in the nursing facility?" Thirty-four of the 42 participants who did not want to leave provided responses: 1) need for a high level of care (n=19; 56%); 2) like nursing facility and/or staff (n=10; 29%); and 3) the nursing facility is the most appropriate placement (n=5; 15%). About one in five (n=24; 20%) indicated that residents were able to transition and preferred to leave.

The next section of the screening instrument provides information about various community-based living arrangements and supportive services. Participants were asked if they thought these housing and service programs were good options for the resident. Among those who responded "no" or "don't know," the interviewer listed Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) and asked whether the respondent would change his or her mind if the resident could get assistance with these tasks. If the participant said "yes" or "don't know," the interviewer proceeded with the next section. If the respondent again said "no," the interview was stopped. For respondents who initially said "yes" to the question about living arrangements and types of support, the interviewer also listed the ADLs and IADLs and asked if assistance in these areas was important for the resident. Fifty-two respondents (43%

of those asked) said either “yes” or “don’t know” to the question of the need for or benefit of support; for these respondents, the interviewer proceeded with the next section.

**Living Arrangements and Assistance**

Among those who continued the screen, interviewers listed potential living arrangements and respondents were able to identify more than one setting. Responses were that if the resident left the facility, he or she: had no place to go (n=17; 33%), would live alone in an apartment or home (n=14; 27%); could live with other family members (n=12; 23%) or with a partner/spouse (n= 3; 6%). Four respondents (8%) said that the resident would be interested in an assisted living facility and seven (13%) indicated an interest in a group home. Note that these responses are self-reports and may not reflect the results of relocation attempts.

To further examine the need for support and the capacity for transitioning, interviewers asked the respondents to evaluate the resident’s need for assistance with ADLs and IADLs. Residents or proxies reported a mean of 5.6 (SD=1.6) IADL difficulties. Most problematic were housework (n=49; 94%), shopping (n=47; 90%), and transportation (n=47; 90%). Residents had a mean of three ADLs (M=3.0, SD=1.7), with the majority needing help with bathing or showering (n=44; 85%) and dressing (n=34; 65%).

**Feasibility of Transitioning**

The interview concluded by asking: “If you had help available for any of these services, would you (your relative) be able to leave the nursing facility?” Although this question is identical to the earlier question about the ability to transition, it was posed after a more comprehensive discussion of preferred living arrangements and services needed. Of the 52 respondents who completed the entire screen, 40 (77%) believed that transitioning was feasible, seven (13%) stated it was not feasible, and five (10%) were unsure. Of the 40 respondents who

believed that leaving the nursing facility was feasible, the majority were self-consenting residents (n=26; 65%) rather than proxies (n=14; 35%,) ($\chi^2$= 8.72, *P*=.013). In short, of the 121 who were initially interviewed, 28 (23%) thought that the resident was currently able to transition, 56 (46%) indicated a preference to leave, and after learning about service and community living options 40 (33%) believed that transitioning was feasible.

**Feasibility of Transitioning: Stability Over Time**

Interviewers approached the 40 participants (77%) who said that transitioning was feasible approximately three weeks later. Most consented to a second interview (n=34; 85%). Of those 68% (n=23) were residents and 32% (n=11) were proxies. Overall, 27 participants (79%) responded with a stable affirmative response toward transitioning; 17 were residents (74% of the resident sample) and 10 proxies (91% of the proxy sample). Among these 27 participants, 81% (16 residents, 6 proxies) completed release forms to enable researchers to refer their cases to a community-based agency.

**Comparison With MDS Preference Question**

Among the 121 residents who consented to the interview, permission was obtained to secure MDS data on 34% (n=41). Preference data from the screen were compared to MDS question Q1a: “Resident expresses or indicates a preference to return to the community.” Of those where a comparison was possible, agreement with our screen and the MDS Q1a was found in 39% of responses (n=16). For 46% of responses (n=19), our interview indicated that the resident preferred to transition and the MDS indicated that the resident did not want to leave ($\chi^2$ = 4.67, p = .097). In one case, the MDS indicated that the resident had a preference to leave whereas our screen found the opposite. Twelve percent (n=5) were unsure if they wanted to leave according to our interview; the MDS was recorded as “no.”

**Comparing Resident Characteristics**

For residents who signed a HIPAA consent, Table 1 compares characteristics of those who indicated that transitioning was feasible with those who stated that transitioning was not feasible. Although the power to identify differences was reduced because only one third of the original sample (n=41; 34%) signed a HIPAA consent, it is clear that participants who thought that transitioning was feasible were less cognitively impaired and younger.

(PLACE TABLE 1 ABOUT HERE)

## DISCUSSION

Given increasing support of consumer choice and state-level policy momentum driven by the Olmstead Decision, rebalancing efforts and Money Follows the Person grants, our goal was to learn about long-stay residents' attitudes about leaving 24-hour facility care. Attempt to interview all Medi-Cal residents or their proxies in eight facilities using no health or functioning exclusion criteria resulted in a sample of 121 (33 residents and 88 proxies) out of 218 eligible to participate (56%). When first asked about residents' current ability to move, the percentage of affirmative responses was less than one-quarter (n=28; 23%). A focus on preference to leave rather than ability, however, resulted in doubling positive responses (n=56; 46%). Finally, after consideration of needs and options, 33% (n=40) considered it feasible to transition from the facility to a lower level of care. As these results indicate, transition is a complicated decision in which the individual weighs both the capacity and the desire to relocate as well as the community support available to meet anticipated care needs. The answer to who would like to transition depends on how the question is asked. We found that despite a high level of preference to transition, three-quarters of respondents believed they lacked the ability to leave. This assessment improved somewhat when community supports were considered, however, safety concerns persisted.

It can be argued that those residents and proxies who believed that transition was feasible were most serious about transitioning. They may be more likely to work closely with community agencies on the complicated tasks of securing housing and arranging for services. Respondents may want to move and believe in their ability to leave, but the discussion of available living arrangements and service needs helped to illuminate potential assistance as well as difficulties prior to stating the feasibility of transitioning.

In terms of stability of the choice to transition, the majority of participants who consented to a second interview continued to believe that transitioning was feasible (n=27; 79%). The instability of the remaining 21% reflects the gravity of the transition decision. This subset could be targeted for further educational or supportive efforts to better understand their fears or concerns. As we could not find another study that reported the stability of residents' preferences toward transition, it is not possible to determine if the design of the screen produced a higher rate of instability than alternative methods of questioning. In practice, more than one interview may be necessary to enable residents and families to reflect on this important decision. Furthermore, 81% of the participants (22 of 27) who completed the release form took a proactive step that demonstrated their commitment to transition. These residents, who were referred to case managers from community-based agencies to begin the transition process and to be linked to services, can be seen as a test of the effectiveness of the screen.

A corollary goal of the study was to compare findings from the California Nursing Facility Transition Screen to the MDS. The MDS assesses preference with a single item that is based largely on the assessor's judgment and cautions assessors against creating unrealistic expectations. With the systematic approach of interviewing all long-stay Medi-Cal funded custodial residents and proxies regardless of their health condition, the screen identified a large proportion of residents who wanted to transition even though the MDS indicated a lack of preference to leave (n=19; 46%). Although about one-third of participants allowed access to their medical records, this finding suggests that a direct questioning approach should be employed and does not create unrealistic expectations because participants acknowledged that some residents needed a high level of care or that the nursing facility was most appropriate. At the same time,

we do not argue that our screen is better than others in use because we cannot find published data about whether other protocols worked with custodial nursing facility residents.

This is a pilot study that explores a previously unaddressed issue in the geriatric literature—long stay residents' perspectives on transitioning out of the facility. Several limitations should be considered. First, the question wording in the screen was not identical to the MDS because the latter does not contain a direct, specific question about relocation. Further complicating the comparison, relatively few people who did not want to transition permitted access to their records. Also, the MDS preference question is only asked upon admission and annually thereafter, so the data could be up to 12 months old. All of the above factors limit our ability to determine if the discrepancy between the MDS and the transition screen is due to method of questioning or timing issues.

Secondly, we did not conduct stability interviews with residents or proxies who said "no" to the move, and some of these participants may later change their mind. We did not repeat these interviews because many proxies were definite that the resident could not move and did not want further contact. Furthermore, the majority of proxies did not permit a second interview with residents to examine reliability issues. Finally, only English-speaking residents were interviewed during this pilot phase.

Our inclusive approach to interviewing all long-stay, custodial residents had two implications, which are not study limitations but rather issues that must be confronted when conducting studies with cognitively-impaired residents. First, respondents who were designated as the residents' proxies had to be approached first, which is necessary unless a new ethical and legal argument can be developed and accepted by Internal Review Boards. Secondly, it is not surprising that many proxy respondents did not consent to the interview even after learning the

purpose of the screen because they stated that the resident was too impaired to move and that the nursing facility was the best living arrangement. Proxies may change their mind if educated about community supports, but these efforts may be unsuccessful in a group that was unwilling to complete a 10-minute interview. The percentage of people who want to transition was determined by dividing the number that expressed this preference by the number that we interviewed. If the denominator included those who refused the interview, then the percentage would be reduced. The former statistic is important for planning purposes if a major relocation effort were initiated.

Although one cannot assume that all self-consenting residents want to relocate, residents who were able to self-consent and who were less cognitively impaired were more likely to express a stable preference to transition. If interviews with all long-stay residents are not feasible in practice, our research suggests that the small group of self-consenting residents are excellent targets for transition and MDS item ‘A9,’ which records the legal proxy decision-maker, could be utilized. Fewer interviews would need to be conducted and a higher number of transition candidates may be identified.

This pilot study represents an important first step in an area with no previous systematic research. We approached and enabled all long-stay, Medi-Cal funded custodial nursing facility residents to express their preferences and beliefs without presumptions as to which residents were good or bad transition candidates. The interview identified a significant proportion of people expressing a preference to relocate, an important population according to the Olmstead principles. In supporting the philosophy of consumer direction, the California Nursing Facility Transition Screen presents both the opportunity and means for long-stay nursing facility

residents to create a different future for themselves and receive the needed resources to meet this goal.

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## CONFLICT OF INTEREST

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Christy M. Nishita: None
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**Author Contributions:** Indicate authors' role in study concept and design, acquisition of subjects and/or data, analysis and interpretation of data, and preparation of manuscript.

Christy M. Nishita was responsible for data entry, analysis and interpretation of data, and the preparation of the manuscript.
Kathleen H. Wilber was responsible for interpretation of data and the preparation of the manuscript.
Saki Matsumoto was involved in data collection and analysis.
John F. Schnelle was responsible for interpretation of data and the preparation of the manuscript.

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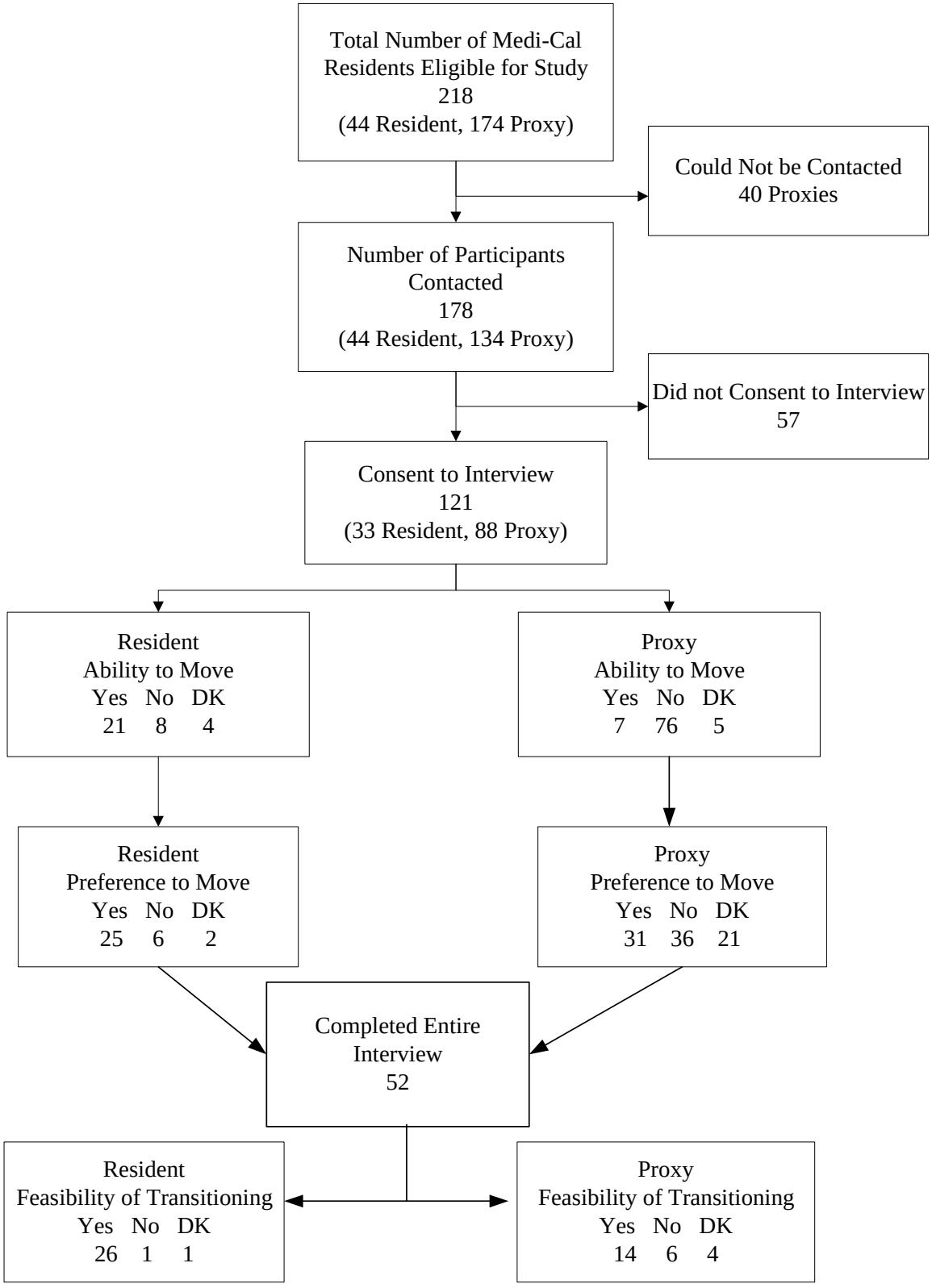
*Figure 1*. Flow of Participants Through the Study



Note: DK= Don’t Know

*Table 1.* Comparison of Participants who Believed that Transitioning was Feasible Versus Those who Indicated that Transition was not Possible Among Participants who Gave HIPAA Consent (Total n = 40)*

| | **Transition Is Feasible (n=30)** | | **Transition Is Not Feasible (n=10)** | |
|---|---|---|---|---|
| Gender | **N** | **%** | **N** | **%** |
| Male | 14 | 46.7% | 2 | 20.0% |
| Female | 16 | 53.3% | 8 | 80.0% |
| Ethnicity | | | | |
| White, Not Hispanic | 14 | 46.7% | 6 | 60.0% |
| Hispanic | 1 | 3.3% | 1 | 10.0% |
| Black | 10 | 33.3% | 3 | 30.0% |
| Asian/Pacific Islander | 4 | 13.3% | 0 | 0.0% |
| American Indian/Alaskan Native | 1 | 3.3% | 0 | 0.0% |
| Marital Status† | | | | |
| Never Married | 13 | 43.3% | 1 | 10.0% |
| Married | 5 | 16.7% | 1 | 10.0% |
| Widowed | 8 | 26.7% | 2 | 20.0% |
| Divorced | 4 | 13.3% | 6 | 60.0% |
| Cognitive Skills for Decision Making‡ | | | | |
| Independent- Decisions Consistent/Reasonable | 17 | 56.7% | 2 | 20.0% |
| Modified Independence- Some Difficulty in New Situations Only | 5 | 16.7% | 1 | 10.0% |
| Moderately Impaired- Decisions Poor, Cues or Supervision Required | 8 | 26.7% | 4 | 40.0% |
| Severely Impaired- Never/Rarely Made Decisions | 0 | 0.0% | 3 | 30.0% |
| Memory | | | | |
| Short-term Memory Problem | 14 | 46.7% | 7 | 70.0% |
| No Short-term Memory Problem | 16 | 53.3% | 3 | 30.0% |
| Long-term Memory Problem‡ | 8 | 26.7% | 7 | 70.0% |
| No Long-term Memory Problem‡ | 22 | 73.3% | 3 | 30.0% |
| | **M** | **SD** | **M** | **SD** |
| Age‡ | 70.6 | 16.1 | 82.2 | 6.3 |
| Number of Diseases/Conditions | 4.7 | 2.7 | 6.0 | 3.3 |
| Number of ADL Tasks in Which the Resident Needs Extensive to Total Assistance | 4.6 | 3.3 | 5.2 | 3.1 |
| Number of Days in the Nursing Facility | 600.8 | 623.9 | 824.8 | 539.3 |

*One participant who signed the HIPAA consent form was excluded from this table because the participant was unsure whether transitioning was feasible or not feasible.

† $p<.05$

‡ $p<.10$